

Cancer Registry Rules

I. Introduction

Title 18, Section 152(a) of the Vermont Statutes Annotated (VSA) requires the Commissioner of Health to establish a uniform statewide population-based cancer registry system for the collection of information determining the incidence of cancer and related data.

These Cancer Registry Rules have been adopted to effect the purposes of the Cancer Registry Law, 18 VSA, Chapter 4.

II. Establishment of Cancer Registry

A Vermont Cancer Registry (VCR) is hereby established within the Department of Health to collect information regarding statewide cancer incidence and related data.

III. Effective Date of Reporting

A health care facility or health care provider diagnosing or providing treatment to cancer patients must report each case of cancer to the Director of the VCR within 120 days of admission or diagnosis as prescribed by these regulations.

The definitions of "health care facility" and "health care provider" appear as Title 18, Section 9432 of the Vermont Statutes Annotated.

IV. Data to be Reported

1. Reportable Cancers

All cancers with a behavior code of "2" (in situ) or "3" (malignant) in the latest edition of the International Classification of Diseases for Oncology (ICD-O) must be reported. However, the following skin cancers, as coded in ICD-O, are excluded from reporting:

- A. 8000-8004 Neoplasms, malignant, NOS of the skin (C44.0-C44.9)
- B. 8010-8045 Epithelial carcinomas of the skin (C44.0-C44.9)
- C. 8050-8082 Papillary and squamous cell carcinomas of the skin (C44.0-C44.9)
- D. 8090-8110 Basal cell carcinomas of any site except genital sites

NOTE: Skin cancers in the genital sites (vagina, clitoris, labium, vulva, prepuce, penis, and scrotum) ARE reportable since they are more likely to metastasize than the usual carcinomas of the skin. (These cancers are reportable both nationally and internationally.)

All benign brain-related tumors occurring in any of the following sites must be reported:

A. The brain, meninges, spinal cord, cauda equine, a cranial nerve or nerves, or any other part of the central nervous system

B. The pituitary gland, pineal gland, or craniopharyngeal duct

2. Data Elements

The following data categories are required to be reported in a machine readable format approved by the Director of the VCR for each case of cancer:

A. Patient Identifiers and Demographics

B. Provider and Facility Identifiers

C. Cancer Identification

D. Extent of Disease at Diagnosis

E. First Course of Treatment

F. Follow-up

No follow-up data needs to be reported prior to January 1, 1995.

V. Quality Control

1. Each health care facility or health care provider shall permit periodic quality control reviews including casefinding, abstracting, coding, and data submission processing. Unless other arrangements are made with a facility or provider, no fewer than 10 working days notice is established as the minimum notice period applicable whenever the VCR wishes to have access to information on site at a facility.

2. The VCR will ensure the provision of cancer registry training and consultation.

3. Reporting facilities shall assist the VCR in annual reconciliation of cancer mortality and incidence data.

VI. Procedure Manual

In order to facilitate reporting and to protect the data collected, the VCR will supplement these regulations with a VCR Procedure Manual which will be made available to all data reporters. Any data fields delineated in the VCR Procedure Manual will be consistent with data sets defined by the American College of Surgeons and the North American Association of Central Cancer Registries.

All identifying information regarding an individual patient, health care provider, or health care facility contained in records of interviews, written reports, and statements procured by the Commissioner of Health or by any other person, agency, or organization acting jointly with the Commissioner in connection with cancer morbidity and mortality studies shall be

confidential and privileged and shall be used solely for the purposes of the study. In accordance with the Cancer Registry Law, the Commissioner shall, however, be able to publish statistical compilations, enter into agreements to exchange information with other cancer registries, and furnish confidential information to other states' cancer registries, federal cancer control agencies, or health researchers.

To ensure the protection and confidentiality of the identifying information collected by the VCR, the VCR Procedure Manual will contain, among other things:

- . Procedures to safeguard and secure the registry database and printed data generated from the database containing identifying information;
- . Procedures to destroy (e.g., by shredding) all printed materials containing identifying information when such materials are to be disposed of;
- . Procedures to make certain that all persons with access to VCR identifying information are aware of the Health Department's Confidentiality Regulation and policy and have signed a written statement acknowledging their responsibility to maintain confidentiality and subjecting them to penalties for violation of confidentiality requirements.18 V.S.A. § 152(a)

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